

ASSEMBLY COMMITTEE
ON
HUMAN SERVICES
Assembly Member Jim Beall, Jr., Chair
Informational Hearing
Friday, November 16, 2007
1:30 - 5:00 p.m.
City of Campbell – Community Center
1 W. Campbell Avenue, Roosevelt Room
Campbell, CA 95008

Testimony
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***Taking the Lanterman Act into the Future:
The SB 1270 Report Recommendations – Expanding Opportunities and Choice
for Individuals with Developmental Disabilities***

3:00 – 3:45 – Setting a Course for Fully Integrated Community Employment

**Program Integration, Information Needs and a
New Blueprint for the
Competitive Employment of Regional Center Clients**

Introduction and Background

Assembly Member Beall, thank you, I am honored to be invited to speak before this Hearing. I manage the California Work Incentives Initiative at the World Institute on Disability in Oakland. We provide Disability Benefits 101 Information Services statewide via the Internet, one on one technical assistance, outreach and training services. In sum, we have “*the right information in the right hands at the right time*” for consumers, family members and providers when regional center youth and adult clients begin to plan employment. Job offers don’t wait around when someone finds an employment opportunity that makes sense to them. Job seekers often have to make an informed choice within marketplace timeframes or lose that paid work opportunity. DB101 addresses these benefits and paid work information realities online in English and Spanish.

The good news is that we know what many of the supports are to improve regional center client employment outcomes and save the government money at the same time. Social Security’s State

Partnership Initiative (SPI projects) over six years in the late 1990s tested the provision of ongoing expert benefits planning information services to two groups of disability beneficiaries with significant mental health conditions who were seeking employment. The extensive Social Security funded benefits planning demonstration was run by California's Department of Rehabilitation. The demonstration research findings from Allen, Shea and Associates validate what benefits planners in the field have known for decades, that is, informed choice pays dividends and improves quality of life.¹

After two years, folks participating in the California SPI project treatment groups had twice as much earned income per quarter, over \$1,000 per quarter, compared with the folks in the project's control groups. After almost four years into the benefits planning demonstration, those who showed marked increased earnings over the first two years also showed a 21% decrease in Medi-Cal covered hospitalization costs. Benefits planning services had paid off for the worker with a disability and for state government over time, and at the same time.

The currently active California Bridges Projects (Youth Transition Demonstration), also funded by Social Security, are showing similar employment results when transition age youth with a significant disability are provided ongoing benefits planning services. A robust 47% of the Bridges Project participants, all youth with a significant disability using public disability benefits, have earned income at minimum wage or above.

That's all good news. The reality check is that these are demonstration projects. This kind of benefits planning information has only recently started to reach, for example, the East Los Angeles Regional Center's Hispanic and Chinese American families.

I trained in East Los Angeles a few weeks ago at The California Endowment headquarters from the kind invitation of the East Los Angeles Regional Center. I worked with young family members with a developmental disability and their families and experienced first hand what Doctor Charlene Harrington shared with us at your last hearing regarding the marked disparity in regional center services to minority groups.² We had one great training day. In the afternoon, after I realized how much the participants were learning about public benefits and paid work scenarios, I asked the family members: "*How are you getting this kind of information now about health coverage and disability benefits and paid work?*" The family members almost became angry with me for asking; they responded in unison, "*We are NOT getting the information you are bringing to us today!*" Then they rattled off a familiar list of agencies they use where they were not getting this benefits planning information, including their regional center.

¹ J. Shea & S. Ekstrom, *California's Individual Self-Sufficiency Planning (ISSP) Project: Final Evaluation Report of a State Partnership Initiative (SPI) Demonstration Project* (Napa, CA: Allen, Shea & Associates, 2004). URL: <http://www.allenshea.com/documents/FinalReport.pdf>

A second source with the actual average earnings cited: J. Shea & S. Ekstrom, *Summary of Impact Estimates: California, Insert for California's Individual Self-Sufficiency Planning (ISSP) Project: Final Evaluation Report of a State Partnership Initiative (SPI) Demonstration Project* (Napa, CA: Allen, Shea & Associates, 2004).

² Taewoon Kang, Ph.D. & Charlene Harrington, Ph.D., *Variation in Types of Service Use and Expenditures for Individuals With Developmental Disabilities*, 2007, supported by funds from NIDRR, the National Institute on Disability and Rehabilitation Research. H133G050358.

Program Integration

So we have a critical information problem which the popular SB 1270 stakeholder meetings documented over and over again. And we know how to solve it, as the benefits planning demonstration data validates. But we also have a systemic program interaction problem. Disability benefit rules, procedures and information, and disinformation, springs forth from all over the place. Multiple providers and circles of support need to know what to do and what to think before a regional center client gets a job offer or wants to start a business. Youth and parents shop for information where they can and where they want. This is the way it is. They often go to the Department of Rehabilitation, the local Social Security field office or One Stop Career Center, or a local non profit organization or parent group.

A Board and Care Operator may have a regional center client resident who is hired at the local community center to work 5pm to 9pm. The new wages may affect the resident's SSI check which is paying the Board and Care Operator for food and rent. The Board and Care Operator is the Representative Payee. How does the regional center support this employment outcome, its information needs, and its circle of support? The answer is that 1) the regional center cannot do it alone, and 2) it cannot do it on the cheap, because I can share twenty other case examples each with twenty different circles of support.

A regional center client working in a sheltered workshop wants to open a micro-enterprise lunch catering business in her neighborhood. Who will advise on the impact of the business on her disability and health coverage benefits? Or about the SSI PASS program that could help her with her situation and setting up the business?

A regional center client with a special needs trust and a conservator accepts a job at the local library three days a week. How does the conservator learn what she needs to know about the impact of the new wages on current Social Security, Medi-Cal or other benefits, including the client's current access to the family's private benefits?

Little about this planning or these outcomes should be outside the IPP process; they are core outcomes for *having* an IPP process.

Outcome-producing benefits planning information services require coherent partnerships of the client's whole circle of support, period. This is not just about the reality that state and federal benefit programs are complex, they are. As well, people are complex, every one of us. Benefits planning services are person-centered, and all of us have complex outcomes over our lives. It is what is. WID works with many benefits planners throughout the state; the successful ones work within a network of coherent partners that share information and resources which support effective procedures to meet common objectives.

A weak or uninformed link in one's circle of support related to the impact of paid work on benefits can and does jeopardize employment. Aunt Martha may know little to nothing about disability benefit rules, but she can be the key influencer in a circle of support. When she states, "*Frank cannot take that job because it will screw up his benefits,*" her decision, not Frank's, affects outcomes. Anecdotally, this is likely in many more cases than a poor job task analysis or a supported employment job match error. It is high time, it is way past high time to fix this decades old information dilemma. Coherent partnerships can fix this problem. In educational

circles nationally we hear about “Communities of Practice,” separate entities working more effectively together to meet common educational objectives. We use the term coherent partner for its concreteness but the needs, goals and objectives are very similar to those initiatives.

Benefits Planning Information Services

The coherent partners that the regional center systems must collaborate with include Social Security Region IX field offices, the local county welfare and Medi-Cal office, the Department of Rehabilitation, California Department of Education and their attendant employment related programming. In turn, a regional center must build and sustain the internal capacity to take responsibility for provision of benefits planning services when requested in the IPP process, at any age.

As we saw when regional centers had enrollment brokers available to clients during the recent rollout of the federal Medicare Part D program, there is a legal foundation to provide seamless access to health care and other benefits in the Lanterman Act. It is not operationalized when employment is an included factor.

New California tools are emerging to support these longstanding informational needs. Many coherent partners are using online tools such as DB101 Information Services, www.db101.org, real time 24/7 accessible information. DB101 provides plain language employment and benefits information tools, including increasingly popular benefits calculators that demonstrate the impact of paid work on individual benefit situations. These accessible tools can build staff capacity across agencies but may still not provide the personal one on one counseling needed. The partners who work with Social Security disability beneficiaries can also access local Social Security funded community based benefits planners (Community Work Incentives Coordinators, CWICs), but there are not nearly enough of them, and not likely to be enough of them for the foreseeable future. (See Benefits Planners link on Home Page www.db101.org)

SB 1270's key recommendation in this area to build sustainable solutions and capacity building is that each regional center should staff at least one full time benefits planner. WID believes this flagship recommendation is the minimum transformational threshold needed so that benefits analysis and assessment can be removed as the employment brick wall it has become. SSI recipients in California can earn almost \$33,000 a year without any threat to their SSI eligibility. While they receive less SSI cash benefits in months they work at these levels, they have never left the program or lost their SSI eligibility due to those earnings. Medi-Cal recipients in California can now earn \$52,000 a year and keep their full scope Medi-Cal by paying an affordable premium in Medi-Cal's eight years old California Working Disabled Program. In the vast majority of regional center circles of support, diverse stakeholders would want the full explanation of how that kind of information really works for their Andrew, or their Frank or Elizabeth. I do not blame them. We can provide that service once we decide to as a community and a government of coherent partners.

Coherent Partners

We view a coherent partner as a paid or an unpaid program and/or individual relationship that exchanges value and supports common goals and objectives.

At the government level, the Governor's Committee on Employment of People with Disabilities, the California Health Incentives Improvement Project (www.chiip.org), Social Security Region IX Field Office Capacity, County Social Services Field Office Capacity must improve the ways they interact with Regional Center benefits planners, who in turn become integrated partners with the California Department of Education, where so much learning begins.

We also think there are ongoing and innovative roles for private charitable foundations. We encourage them to continue to provide resources for these common goals. They can help initiate local start up projects that support new ways to shape coherent partnerships, enabling circles of support to embrace competitive employment for regional center clients, not run from it.

On behalf of consumers with disabilities and their advocates who have surfaced over the past two years to support improvements to Medi-Cal's California Working Disabled Program, and who are engaged with these efforts through the statewide GAPS Task Force staffed by WID, I want to thank you Assembly Member Beall for your leadership in these fall Hearings, and for your willingness to embrace difficult systems change over your tenure in our Assembly.

The regional center system challenge to shift and support competitive employment initiated as a result of these hearings will reverberate through other systems change in Medi-Cal so that integrated programs are responsive to employment needs of these Californians early on in this century.

Combined, SB 1270 and Medi-Cal reforms can reshape the culture; the new culture's circles of support will have their needs met when family members receive the full inclusionary employment services they ask for, on time.

Public Policy Implications and Recommendations

Our view for some time has been that we must retool state and federal infrastructure as we reshape the community culture, not retool a single program.³ DB101 has trained thousands of cross agency service provider participants in 20 of California's 58 counties since 2003 on health care, benefits, paid work and disability. The job is large and comprehensive, but the steps to take are possible and do-able. As noted above, Social Security funds demonstration projects that build the research and data case for benefits planning. CMS (Centers for Medicaid and Medicare Services) funds a majority of California's DB101 training activities and other major California health coverage and work related activities through a Medicaid Infrastructure Grant (MIG).⁴

Recommendation One: Competitive Employment First!

Let me offer the direction for a legislative design by quoting and then paraphrasing Doctor Paul Wehman, Ph.D., whom many of you are familiar with since the 1970s for his tremendous contribution to supported employment. He is emphatically focused when he states:

“Competitive Employment First!” To paraphrase the approach of this supported employment scholar from Virginia Commonwealth University:

*A critical philosophy needs to permeate all adult service and secondary special education/transition programs requiring ongoing attention to the following question: Is competitive employment the first choice for persons with significant disabilities? Are service providers and teachers promoting competitive employment first as opposed to segregated placements? Are families encouraging persons with disabilities to try real work for real pay first?*⁵

We posit that legal infrastructures should require that coherent partners build integrated programming based on these questions.

WID endorses and highly recommends implementing the SB 1270 recommendation that all 21 regional centers seek the funding (or re-allocate funding available with vacant FTE positions) to staff at least one full time benefits planner/benefits planning service coordinator. Implementation can begin now prior to needed legislation by reallocating existing resources.

It is not practical from our experience to vendorize the entire benefits planning service menu. To meet the challenge of effective benefits planning services, the regional center needs:

- 1) a threshold baseline of in-house expertise, or it will not gain the internal expertise of what a quality vendor is in this field to supplement services; and,

³ WID was the sponsor in 2002 of the Workforce Inclusion Act (Aroner), source for the now in place *California Comprehensive Strategy for Employment of People with Disabilities*, a policy framework outlining better strategic partnerships between the Health and Human Services and Labor and Workforce Development Agencies for workers and job seekers with a disability. Available at: <http://www.edd.ca.gov/gcepdind.asp>

⁴ California's multi year Medicaid Infrastructure Grant (MIG) is administered by Sonoma State University's California Health Incentives Improvement Project (www.chiip.org).

⁵ Paul Wehman, Ph.D., *Invited Commentary to “The Quest for Ordinary Lives”: Integrated Employment: If Not Now, When? If Not Us, Who?*; 2006, Professor of Physical Medicine & Rehabilitation, Virginia Commonwealth University.

2) an internal commitment and resources to establish and build local coherent partnerships for the benefits planner to effectively support employment outcomes.

We propose that at least four and up to six regional centers both self select and be selected to set a five year course to the measurable outcome that competitive employment is the expected, routine and planned norm for youth and other clients with a developmental disability.

Other employment options remain available for reasonable amounts of time, and within an IPP driven review process. The selected regional centers would retool and redesign their infrastructure so that at the end of the five year redesign and implementation, significant data emerges that shows increased competitive employment outcomes because of the necessary benefits planning and other employment supports in place that help effect the new outcomes and data trends.

To study effects, half of the regional centers participating in the five year redesign would commit to and design for the elimination of their use of subminimum wage certificates in their cachement area by the end of the first five years.⁶

The IPP process in all participating regional centers would provide their clients who work under a subminimum wage certificate routine, scheduled, proactive reviews of their employment options and capacities.

The redesign period will include forging the coherent partnerships needed as well as realign or seek the needed funding to put in place appropriate supported employment services. This must include funding or realigned funding from vacant FTE positions for at least one full time expert in-house benefits planner/benefits planning regional center coordinator.

The new blueprint is adapted from SB 1270 Goal #1.

From:

May 2007 SB 1270 Report to the Governor

Goal 1. July 1st 2008, opportunities for integrated employment and community participation are discussed at all Individual Program Plan meetings.

Recommendation #1: Make sure people with developmental disabilities and families get information about integrated employment, community participation, work and health benefits at their IPP meeting.

Strategy #1.1 Options for integrated employment, community participation, and benefits planning are included in the Individual Program Planning (IPP) process by July 1st, 2008.

⁶ Ibid. (Wehman) page 6.

Description: Adjustments are made to Regional Center IPP training materials, procedural guidelines and assessments for transition-aged youth and adults to include resource information about options for integrated employment and community participation that reflect the individual's lifestyle, culture, language and spiritual preference, as well as income, health, and educational benefits (in the primary language of the individual). Planning should start with the assumption that all individuals, if they choose, can be involved in income-producing activities and be active members of their community. As agreed upon by the individual's planning team, goals and objectives regarding employment, community participation, and benefits planning are developed and, if needed, regional center resources are allocated.

Strategy #1.2 Consistent with the Workforce Inclusion Act (AB 925) and the efforts of the Governor's Committee, the Council recommends adding a benefits planner position to the Regional Center core staffing formula by July 1st, 2008.

Description: This regional center or contract, trained expert position (one per 4,000 persons served) would:

- (1) provide benefits (including Social Security, Medi-Cal or other benefit programs) and financial planning assistance to individuals served by the regional center;
- (2) support the development of an individual benefits analysis by service coordinators or service providers;
- (3) communicate with local Social Security representatives to determine benefit type, levels, previous use of work incentives;
- (4) assist individuals, family members, or service providers in reporting wages and other information to Social Security;
- (5) with and on behalf of individuals, advocate with Social Security to clarify issues and ensure equal application of work incentives and other rules; and, (6) provide in-service trainings on Social Security work incentives, Medi-Cal or other benefit programs to individuals with developmental disabilities, family members, regional center staff, service providers, and other support service personnel. All services, supports and materials will be provided in local threshold languages.

Recommendation Two: Make Work Pay for Social Security Disability Beneficiaries

New legislation should require that the Director of the Department of Developmental Services 1) seek the appropriate state partners and 2) craft and 3) submit within a fixed timeline a proposal to the Social Security Administration (SSA) and the Centers for Medicare and Medicaid Services (CMS) for approval of a California statewide ten year demonstration project that promotes and supports competitive employment for very low wage SSI, SSDI and Childhood Disability Beneficiaries (CDB) of the Social Security Disability Programs. The State of California needs to provide this leadership as federal agencies in the area of benefits and work have become unfocused and fragmented in recent years.

- The demonstration project would feature a “hold harmless” permanent, SSI, SSDI and CDB earned income disregard for all gross monthly earnings below the yearly indexed Social Security Substantial Gainful Activity level (\$900 per month in 2007); and,
- Include improved SSI asset building and other design features to be assessed, inclusive of features from the SB 1270 Report. See below.

From:

May 2007 SB 1270 Report to the Governor

Recommendation #8: For people who work and get SSI, let them keep more of the money they earn and health benefits.

Strategy #8 Develop a request to the Social Security Administration (SSA) and the Centers for Medicare and Medicaid Services (CMS) for a ten year “hold harmless” statewide demonstration for CA SSI recipients and/or SSDI beneficiaries by March 31st, 2008.

Description: The State Council in collaboration with the World Institute on Disability and the Governor’s Committee will work with the Health and Human Services Agency, the Department of Developmental Services and the Department of Health Services (Medi-Cal/IHSS) to develop a waiver request for the Governor’s approval and submission to SSA and CMS.

Core design elements will include:

- ☐ *An SSI monthly, earned income disregard equal to the current, indexed Substantial Gainful Activity (SGA) levels (annually indexed by SSA, \$900 per month in 2007).*
- ☐ *Monthly earned income above SGA through statewide pilot of a monthly 1:4 earned income disregard waiver for SSI recipients.*
- ☐ *A significant raise in SSI recipient asset level restrictions for demonstration purposes (e.g., Florida has an SSA approved asset level waiver of \$10,000) and allowed to remain in place for demonstration participants after the term of the demonstration (hold harmless).*
- ☐ *Accessible, expert Social Security and CA social services work incentives staff available throughout the demonstration.*

Demonstration goals include:

- (1) simplify the rules for all SSI low wage earners;
 - (2) integrate the rules for Social Security disability beneficiaries seeking higher levels of self-sufficiency; and
 - (3) seamless access to health coverage when working or not working.
- SSA has used pilots of waivers (e.g., a reduction of SSI benefits by \$1 for every \$4 instead of the current \$2 of earnings in excess of \$65) to determine their effects on employment and the use of SSI and other public benefits.

However, pilots have typically been used in studies with small numbers of participants. This pilot would provide SSA with the numbers of participants needed to make definitive impact statements.

I conclude with a request that you understand my background and my work with youth and adults with a developmental disability and employment since 1980. I know full well that not every single regional center client can work at competitive wages. This blueprint is built on self-determination and personal choice. I know full well that most adult disability program rules require legal evidence that the applicant cannot work for at least twelve months before they can access health coverage and benefits. And I know full well from field experience and the ample research that this has never meant, legally or realistically, that the disability beneficiary is a permanent vocational failure in the flourishing marketplace that is California.

This is a blueprint to put the consumer in charge with informed choice and access to the diversity of work options each person deserves. The recommendations can effect major change in the employment outcomes of regional center clients. The coherent partnerships required are possible when State leadership takes control and owns the problems that we are convinced are completely solvable. Thank you for your time. I can take your questions.

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